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The Patient Rights Advocate: Redefining the Doctor-Patient Relationship in the Hospital Context

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I. INTRODUCTION

As Western man approaches the last quarter of the twentieth century, he is developing the power to control the forces of nature.¹ Few areas of human behavior have not been affected by new technologies. In health care, progress has been dramatic in such areas as the determination of prenatal genetic defects through amniocentesis,² asexual reproduction through artificial insemination,³ the use of an artificial placenta,⁴ cloning,⁵ artificial modification of man—especially through transplantation,⁶ modification of human behavior through psychosurgery and chemotherapy,⁷ and the mechanical postponement of death.⁸ No aspect of health care has escaped the impact of technology.

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1. See, e.g., D. CALLAHAN, ABORTION (1968); P. LAURIE, DRUGS (1967); V. MARK & F. ERVIN, VIOLENCE AND THE BRAIN (1970); J. NOONAN, CONTRACEPTION (1965); Chorover, *Big Brother and Psychotechnology*, PSYCHOLOGY TODAY, Oct. 1973, at 43. See generally M. BROWN, THE SOCIAL RESPONSIBILITY OF THE SCIENTIST (1971).

2. See J. GAVER, BIRTH DEFECTS AND YOUR BABY 34-39 (1972).

3. See J. FLETCHER, MORALS AND MEDICINE 100-41 (1954); P. RAMSEY, FABRICATED MAN: THE ETHICS OF GENETIC CONTROL 104-61 (1971); A. ROSENFELD, THE SECOND GENESIS 158-64 (1972); N. ST. JOHN-STEVAS, LIFE, DEATH AND THE LAW 116-59 (1961).

4. See G. LEACH, THE BIOCRATS 284-325 (1970); G. TAYLOR, THE BIOLOGICAL TIMEBOMB 56-90 (1968).

5. See G. LEACH, *supra* note 4, at 110-15; P. RAMSEY, *supra* note 3, at 60-103.

6. See D. FISHLACK, MAN MODIFIED 157-95 (1971); G. LEACH, *supra* note 4; E. MENDELSON, J. SWAZEY & I. TAVISS, HUMAN ASPECTS OF BIOMEDICAL INNOVATION 3-46 (1971); G. TAYLOR, *supra* note 4.

7. See *Quality of Human Care—Human Experimentation, 1973, Hearings Before the Senate Subcomm. on Health of the Comm. on Labor and Public Welfare, 93d Cong., 1st Sess., pt. 2, at 337-791*; V. MARK & F. ERVIN, *supra* note 1.

8. See G. TAYLOR, *supra* note 4, at 91-124; Birch & Moore, *Organ Transplantation in New England*, 287 NEW ENG. J. MED. 129 (1972); Sanders & Dukeminier, *Medical Advance and Legal Lag: Hemodialysis and Kidney Transplantation*, 15 U.C.L.A.L. REV. 357 (1968); TIME, Jan. 1, 1973, at 38.

While advancing technology has demonstrated how much of our lives is governed by human intervention, it also forces the recognition that such power reshapes man's own nature and brings with it awesome responsibilities. In the words of Herman Kahn and Anthony J. Wiener:

Man is developing enormous power to change his own environment. . . . The prevailing secular humanist view is that this is "progress." . . . Yet this very power over nature threatens to become a force of nature that is itself out of control, as the social framework of action obscures and thwarts not only the human objectives of all the striving for "achievement" and "advancement," but also the various inarticulate or ideological reactions against the process. . . . [I]f we cannot learn not only to take full advantage of our increasing technological success, but also to cope with its dangerous responsibilities, we may only have thrown off one set of chains—nature-imposed—for another, ostensibly man-made, but in a deeper sense, as Faust learned, also imposed by nature.⁹

It is no longer necessary to wait passively for an illness to run its course or for death to come. The issue now is who exercises how much power to make what decisions affecting the health care of an individual. Such decisions involve the selection of one course of action from several available, and there can be no dispute that individual patients have an interest in the decision-making process.

The attention of the American people on patients' rights has been stimulated by a series of well-publicized medical events. The most dramatic include: the prolongation of the life of former President Harry S. Truman by heroic means;¹⁰ the disclosure of an experiment financed by the Public Health Service in which black men with syphilis were not treated despite the known dangers and lack of informed consent;¹¹ the revelations concerning experiments on aborted fetuses;¹² the Supreme Court abortion decisions;¹³ and the widespread influence of medical media, both fiction—"Marcus Welby," "Medical Center," "The Bold Ones"—and fact—"House Call," "N.B.C. Reports."¹⁴ In addition, the release of the final report of the Secretary's Commission on Medical Malpractice¹⁵ has had an

9. H. KAHN & A. WIENER, *THE YEAR 2000: A FRAMEWORK FOR SPECULATION ON THE NEXT THIRTY-THREE YEARS* 412 (1967); cf. N. DAVIS, *LAWRENCE AND OPPENHEIMER* (1968).

10. See *TIME*, Jan. 8, 1973, at 55.

11. See *MED. WORLD NEWS*, Aug. 18, 1972, at 15.

12. See 119 CONG. REC. 4166-75 (daily ed. May 31, 1973); *MED. WORLD NEWS*, Oct. 5, 1973, at 32.

13. *Roe v. Wade*, 410 U.S. 113 (1973); *Doe v. Bolton*, 410 U.S. 179 (1973).

14. See Byrnes, *Media and Medical Malpractice*, in HEW, APPENDIX, REPORT OF THE SECRETARY'S COMMISSION ON MEDICAL MALPRACTICE 653 (1973) [hereinafter cited as HEW APPENDIX]; Davidson, *Viewer Heal Thyself!*, *TV GUIDE*, July 21, 1973, at 21.

15. HEW, REPORT OF THE SECRETARY'S COMMISSION ON MEDICAL MALPRACTICE (1973) [hereinafter cited as HEW REPORT].

impact. As the Commission reported:

Within the span of one human lifetime we have gone from the days of the horse-and-buggy doctor to the modern, thousand-bed medical center with all of its nigh-unbelievable sophistication. Today's physicians routinely save the lives and preserve the health of countless patients to whom the old-time physician could offer only death-bed solace. . . . New drugs, new techniques, and new machinery bring with them new risks, and no degree of professional competence and training can guarantee a successful outcome in every medical case.

Medicine, too, for all its widely-heralded accomplishments, is still more art than science.¹⁶

Although the general topic of the right to health care itself is important,¹⁷ this article focuses on efforts to protect the patient's interests in the exercise of his rights. We begin with two fundamental propositions: (1) the American medical consumer possesses certain interests, many of which may properly be described as "rights," that he does not automatically forfeit by entering into a relationship with a doctor or a health care facility; and (2) most doctors and health care facilities fail to recognize the existence of these interests and rights, fail to provide for their protection or assertion, and frequently limit their exercise without recourse for the patient.

Because a sick person's first concern is to regain his health, he is willing to give up rights that otherwise would be vigorously asserted. Moreover, the doctor-patient relationship as it exists in the hospital—where the most critical decisions are made and where most people receive their primary care—effectively removes the patient from any participation in the medical decision-making process. This article argues that one does not relinquish basic human rights upon entering a health care institution, that these rights can be protected without fear of decreasing the efficacy of medical treatment, and that protecting these rights requires a return of medical decision-making power to the patient and a legal redefinition of the doctor-patient relationship. The foundation for protecting the patient's interests within the health care facility is a clear, comprehensive statement of the rights of the patient. A statement alone, however, is neither self-enforcing nor does it guarantee protection of the patient's interests. To ensure such protection, this article suggests the patient rights advocate as an enforcement mechanism.

16. *Id.* at 1.

17. See generally Cantor, *The Law and Poor People's Access to Health Care*, 35 *LAW & CONTEMP. PROB.* 901 (1970); Curran, *The Right to Health in National and International Law*, 284 *NEW ENG. J. MED.* 1258 (1971); Szasz, *The Right to Health*, 57 *GEO. L.J.* 734 (1969).

II. LEGAL REDEFINITION: THE LEGACY OF THE AMERICAN LEGAL SYSTEM

It is necessary at the outset to dispel the common objection that the legal system has no legitimate interest in "interfering" with the doctor-patient relationship. Even a cursory glance at the legal history of the past century demonstrates the weakness of this argument. In myriad situations, the judiciary, the legislature, and the chief executive have exercised novel and widespread control over previously protected relationships. For example, the enactment in 1935 of the National Labor Relations Act¹⁸ substantially redefined the employer-employee relationship, and subsequent amendments¹⁹ and judicial decisions²⁰ continually refined and adjusted the balance of power between labor and management. Similarly, the federal securities acts have made far-reaching changes in at least two fundamental corporate contexts—the relationship between a corporation and its shareholders²¹ and the relationship between a purchaser and a seller of securities.²² In both cases, the courts and the Securi-

18. Act of July 5, 1935, Pub. L. No. 74-198, §§ 1-13, 49 Stat. 449 (codified at 29 U.S.C. §§ 151-68 (1970)). This Act was passed to protect "the right of employees to self-organization and to the selection of representatives of their own choosing for collective bargaining without restraint or coercion." *NLRB v. Fansteel Metallurgical Corp.*, 306 U.S. 240, 255 (1939). The protective policies of the Act were largely responsible for the rise of unionism and collective bargaining—a dramatic change in American labor relations. See C. MORRIS, *THE DEVELOPING LABOR LAW* 35-36 (1971).

19. By 1947 it was thought that unions had derived too much economic power from the rights granted them in the 1935 legislation. Therefore, Congress amended the NLRA by enacting the Labor-Management Relations Act, Act of June 23, 1947, Pub. L. No. 80-101, §§ 1-503, 61 Stat. 136, which was designed in part to restore equality of bargaining power between labor and management. See F. DULLES, *LABOR IN AMERICA* 355-60 (3d ed. 1966).

In order to regulate intraunion relationships and to curb abuses in internal union government, Congress further amended the NLRA by passing the Labor-Management Reporting and Disclosure Act, Act of Sept. 14, 1959, Pub. L. No. 86-257, §§ 1-707, 73 Stat. 541.

20. The courts have found it necessary to deny protection to certain concerted employee activities that were arguably privileged under § 7 of the NLRA, 29 U.S.C. § 157 (1970). See, e.g., *NLRB v. IBEW Local 1229*, 346 U.S. 464 (1953) (disloyalty by employees not on strike); *Automobile Workers Local 232 v. Wisconsin Employment Relations Bd.*, 336 U.S. 245 (1949) (intermittent and unannounced work stoppages); *NLRB v. Sands Mfg. Co.*, 306 U.S. 332 (1939) (strike in violation of collective bargaining agreement). In each case, the Court refined the employer-employee relationship beyond the broad commands of the statute.

21. Section 14 of the Securities Exchange Act of 1934, 15 U.S.C. § 78n (1970), broadly regulates the solicitation of shareholder proxies in an attempt to promote informed corporate suffrage. See *Mills v. Electric Auto-Lite Co.*, 396 U.S. 375 (1970). In addition, § 16(b) of the '34 Act, 15 U.S.C. § 78p(b) (1970), prohibits 10% shareholders and other insiders from retaining short-swing profits gained from the sale of their corporation's stock. See generally Lowenfels, *Section 16(b): A New Trend in Regulating Insider Trading*, 54 CORNELL L.Q. 45 (1968).

22. Perhaps no relationship has been regulated more pervasively than that between the

ties and Exchange Commission have been quick to redefine further the relationship in order to implement more effectively the purposes of the federal legislation.²³ In the field of consumer law, courts and legislatures have reshaped the right-duty relationships between buyer and seller²⁴ and between debtor and creditor.²⁵

The foregoing are but a few examples of the many individual relationships that have been redefined by governmental bodies.²⁶ Hopefully these examples make it clear that the prior establishment by law or custom of a relationship is not in itself sufficient justification for its unchanged continuation. Moreover, when basic constitutional rights or fundamental human fairness provide sufficient justi-

purchaser and the seller of securities. For example, the registration requirements centering around § 5 of the Securities Act of 1933, 15 U.S.C. § 77e (1970), provide a detailed set of rights and duties applicable to the participants in a distribution of securities. *See, e.g.,* Escott v. BarChris Constr. Corp., 283 F. Supp. 643 (S.D.N.Y. 1968).

23. One of the most striking judicial definitions of a relationship has come in the context of the expanding civil liability under § 10(b) of the Securities Exchange Act of 1934, 15 U.S.C. § 78j (1970), and under SEC Rule 10b-5, 17 C.F.R. § 240.10b-5 (1973). The courts have given detailed substantive content to the terse provisions of the Rule, thereby redefining the purchaser-seller relationship according to the changing judicial theories of securities regulation. *See* Superintendent of Ins. v. Bankers Life & Cas. Co., 404 U.S. 6 (1971) (10b-5 invoked as a remedy for corporate mismanagement); Shapiro v. Merrill Lynch, Pierce, Fenner & Smith, Inc., 353 F. Supp. 264 (S.D.N.Y. 1972) (duty of disclosure placed on insider who trades on an exchange).

24. Article 2 of the UNIFORM COMMERCIAL CODE constitutes a general redefinition and codification of the purchaser-seller relationship. Of particular note is § 2-302, which allows a court to refuse enforcement of a clause or contract that it finds unconscionable. This section apparently is a legislative mandate for continuing judicial readjustment of commercial consumer relationships. *See* State v. ITM, Inc., 52 Misc. 2d 39, 275 N.Y.S.2d 303 (Sup. Ct. 1966) (fraudulent referral sales program); *cf.* Henningsen v. Bloomfield Motors, Inc., 32 N.J. 358, 161 A.2d 69 (1960) (disclaimer of warranty on automobile).

25. Although enacted by only a handful of states, the UNIFORM CONSUMER CREDIT CODE would define and harmonize the debtor-creditor relationship in the context of small loans, installment loans, and other consumer credit transactions. *See generally* Malcolm, *The Uniform Consumer Credit Code*, 25 BUS. LAW. 937 (1970). Congress also acted to define the rights and duties between debtor and creditor when it passed the Consumer Credit Protection Act, 15 U.S.C. §§ 1601-77 (1970), and the Fair Credit Reporting Act, 15 U.S.C. §§ 1681-81t (1970). Even in the absence of a specific statute, the courts have been active in shaping the debtor-creditor relationship. *See* Fuentes v. Shevin, 407 U.S. 67 (1972) (use of provisional remedies without notice and hearing violates due process); Unico v. Owen, 50 N.J. 101, 232 A.2d 405 (1967) (holder in due course status denied to financier closely related to original seller).

26. Other relationships that have been redefined include warden-prisoner, *see* D. Rudovsky, *THE RIGHTS OF PRISONERS* (1973); police-suspect, *see, e.g.,* Miranda v. Arizona, 384 U.S. 436 (1966) (right to remain silent); Gideon v. Wainwright, 372 U.S. 355 (1963) (right to counsel); mental patient-administrator, *see* Wyatt v. Stickney, 344 F. Supp. 373 (M.D. Ala. 1972); B. ENNIS & L. SIEGEL, *THE RIGHTS OF MENTAL PATIENTS* (1973); student-teacher, especially with regard to the expression of political opinions, *see* Tinker v. Des Moines Independent Community School Dist., 393 U.S. 503 (1969); Burnside v. Byars, 363 F.2d 744 (5th Cir. 1966); and officer-soldier, *see* R. Rivkin, *THE RIGHTS OF SERVICEMEN* (1972); R. Rivkin, *GI RIGHTS AND ARMY JUSTICE* (1970).

fication, the legislature, the judiciary, and the executive can and will act to redefine the relationship. The process of redefinition may take many forms, including federal or state legislation, administrative action, injunctive relief, or an executive order. Whatever the form, the effect is qualitatively the same. Usually there is an interim stage in the process of redefinition in which the legislature or the judiciary, recognizing its lack of competence in particular areas of specialization, encourages and sanctions the development of solutions by the parties themselves. These observations suggest that a legal redefinition of the doctor-patient relationship is neither a radical nor an unprecedented suggestion.

III. RIGHTS AND DUTIES

Attempts to redefine the balance of power between doctor and patient and between hospital and patient focus on the limits of personal interaction delineated by such concepts as rights, duties, privileges, and liabilities.²⁷ The right-duty concept affects at least

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27. The statement "I have a right" performs several functions and has several different meanings. The particular function and meaning are generally not made clear to the listener and may not even be clear to the person making the statement. Possible meanings include:
- I. "Because I am a citizen of this country, I possess *x* as a legal right created by the Constitution, by legislative action, or by prior court determination."
 - II. "Because of my relationship with another party, there is a strong possibility that a court of law would recognize *x* as my legal right."
 - III. "I believe that *x* should be recognized as a right even though a court of law would probably not recognize it as such."

As these examples demonstrate, there is no single or absolute definition. To understand any definition, it is necessary to understand the purpose for which the definition is sought, the audience for which it is intended, and the identity of the definer. In regard to the concept "right," it is most helpful to consider that a continuum exists. At one end would be all of those "rights" that are recognized as legal rights. These include the rights of citizenship arising under the Constitution and its amendments, the laws of the 50 states, and court decisions. Holland, in his treatise on jurisprudence, refers to such a right as "a capacity residing in one man of controlling, with the assent and assistance of the State, the actions of others." T. HOLLAND, *THE ELEMENTS OF JURISPRUDENCE* 83 (12th ed. 1916). This is the type of right described in statement I.

Somewhere near the middle of the continuum are those rights that would be considered by a court of law (not subject to dismissal under FED. R. CIV. P. 12 (b)(6)), with a high degree of possibility that the court would recognize them as legal rights. In most situations, all that is needed is the appropriate justiciable controversy to present the court with the opportunity to recognize a "new" legal right. This type of right involves a reasonable expectation of what a court of law would do if called upon to deal with the issue. This type of right is described by statement II.

At the other end of the continuum are statements of what the law "ought" to be, based upon a political or philosophical conception of the nature and needs of man. In declaring what we believe should be, we are making a political statement. Such "rights" may be considered of fundamental importance and preexist recognition by positive law. The early civil rights movement provides numerous examples, as does the United Nations Universal Declaration

three specific areas of decisions concerning the health care of the individual: the right to the whole truth, including information that is part of medical records both during and after treatment; the right to privacy and personal dignity; and the right to retain self-determination. The manner and extent to which these rights exist and are in need of protection can be seen by considering the interaction between the health care facility and the patient in chronological form. In the following list, the word "right" is used to denote those rights that would be recognized at law as well as those that should be recognized either at law or as a matter of internal hospital policy.

Selection of the Health Care Facility

—Does the potential patient have a right to know the available medical resources within the community?

—Does the potential patient have a right to know what research and experimental protocols are being used by the doctor and by the health care facility, and to know what alternatives exist for treatment?

—Does the potential patient have a right to know in advance what rights are afforded him as a patient at a medical facility?

—Does the potential patient have a right to the highest quality medical treatment available?

—Does the potential patient have a right to the highest degree of care without regard to the source of payment for that care?

—Does the potential patient have a right to complete secrecy concerning the source of payment for treatment and care?

Entering the Health Care Facility

—Does the patient have a right to prompt attention in an emergency situation?

—Does the patient have a right to know the identity and level of professional training of all those providing treatment?

—Does the patient have a right to have each and every form that must be signed carefully explained and the significance of each consent clarified?

—Does the patient have a right to a review of his preliminary

of Human Rights. This is the kind of right described in statement III.

For other attempts to define the term "right" and reflections upon the relationship based on that definition see J. AUSTIN, *THE PROVINCE OF JURISPRUDENCE DETERMINED* (1954); W. HOHFELD, *FUNDAMENTAL LEGAL CONCEPTIONS* (1923); E. POLLACK, *HUMAN RIGHTS* (1971).

diagnosis to protect against premature labeling of his condition?

—Does the patient who does not speak English have a right to an interpreter?

While in the Health Care Facility

—Does the patient have a right to a clear, complete, and accurate evaluation of his condition?

—Does the family of the patient have a right to a clear, complete, and accurate evaluation of his condition?

—Does the patient have a right to all the information contained in his medical record?

—Does the patient have a right to discuss his condition with a consultant-specialist at his own request and expense?

—Does the patient have a right to a detailed explanation, in layman's terms, of every diagnostic test, treatment, procedure, or operation, including alternative procedures, costs, risks, and the identity and qualifications of the person actually performing the procedure?

—Does the patient incapable of informed consent have a right to the appointment of a guardian who is not a member of his family?

—Does the patient have a right to know whether a particular test or procedure is for his benefit or for educational purposes?

—Does the patient have a right to refuse any particular drug, test, or treatment?

—Does the patient have a right to both personal and informational privacy with respect to the hospital staff, other doctors, residents, interns, and medical students, any type of researcher, nurses, and other patients?

—Does the patient have a right of access to the "outside world" by means of visitors and a telephone, or to limit such access as he sees fit?

—Does the patient have a right to refuse to leave the health care facility if he feels it would seriously endanger his health?

—Does the patient have a right to leave the health care facility regardless of physical condition or financial status?

After Termination of the Hospital-Patient Relationship

—Does the patient have a right to a complete copy of the information contained in his medical record?

—Does the patient have a right to continuity of care by means of access to the doctors who provided treatment while he was in the health care facility?

The degree to which the patient retains any power of self-determination depends on the resolution given these questions, on the legal delineation of his interests, and on the strength of the mechanism created to assert and protect his rights. In this connection, it is instructive to look at the recent historical development of the doctor-patient relationship in the hospital context.

IV. THE TRADITIONAL DOCTOR-PATIENT RELATIONSHIP AND ATTEMPTS TO RESOLVE HEALTH CARE CONFLICTS

The traditional doctor-patient relationship model takes a "doctor knows best" position for granted. The individual doctor evaluates the needs of the patient, determines what the patient can be told, and provides only that information. The health care facility carries out the wishes of the doctor. All major medical decisions are made by the doctor, who derives his authority and responsibility from the traditional concept of the doctor-patient relationship.²⁸ This formulation, however, has failed to keep pace either with the parallel historical developments in areas such as employer-employee relationships discussed above or with developments in the field of medicine itself.

As recently as the turn of the century, a patient had less than an even chance of benefiting from an encounter with a physician. Physicians were just beginning to emerge from the era when they were essentially tradesmen, often with little more to offer their patients than comfort and company during illness and death. The principal causes of mortality were the infectious diseases against which the medical community stood impotent. There were few medical schools, few diagnostic tests, no specific treatment of disease, and no specialization of physicians.²⁹ During the past century, however, medical progress has brought about a radical change in the doctor's ability to diagnose and treat disease. Infectious disease has all but been conquered—such chronic diseases as heart disease have become the major killers. Hospitals have replaced "pest houses,"³⁰ and medical education has become increasingly demanding and

28. See generally T. PERCIVAL, *MEDICAL ETHICS* (1927).

29. In the words of former American Medical Association President Dwight L. Wilbur, "It is difficult to accept that physicians of that day and this were even in the same profession." Wilbur, *Let's Lead Rather than Be Led*, 62 J. TENN. MED. ASS'N 607 (1970). Depending on the index used, one can still argue persuasively that a majority of patients continue to receive "inadequate" care. See Brook & Appel, *Quality of Care Assessment: Choosing a Method for Peer Review*, 288 NEW ENG. J. MED. 1323 (1973).

30. See Knowles, *The Hospital*, 229 SCI. AM. 128 (1973).

exact.³¹ As technology has increased the doctor's ability to deal effectively with more health-threatening situations, it has also widened the gulf between doctor and patient. More problems can be diagnosed and treated, the doctor's time is more in demand, and he has less time to spend with his patient to develop a working relationship of trust and mutual respect. As medical advances become more subtle and complex, explaining diagnoses, procedures, treatments, and alternatives to the patient becomes more difficult. Concurrently, widespread publicity—especially through television and newspaper coverage of medical break-throughs and portrayal of medical crisis resolutions in fiction—generates greater public expectations. Though some way must be found to restore the expectations of the medical consumer to reality, there is a sense in which such expectations represent the inadequacies of the present doctor-patient and hospital-patient relationships. The doctor's position has been strengthened and the patient's weakened by technological advances; it is no longer beneficial to the patient to maintain the doctor-patient relationship of 140 or even 40 years ago. Too much has changed.

Nevertheless, physicians continue to argue that the "traditional doctor-patient relationship" must be maintained at all costs. Although the tremendous changes in the content and context of that relationship over the past century seem to undermine this argument, the advantages from the doctor's perspective of maintaining such a "traditional" relationship are many. Accountability for actions is likely to be restricted to peer review. Public scrutiny of medical decision making is likely to be minimal. Autonomy of action is likely to be maximal. Patient-consumer influence on services rendered is not likely to be significant.

The maintenance of the traditional doctor-patient relationship in a modern hospital context has generated many problems that characterize present day medical decision making. First, both the decision maker—the party with the actual power to make a treatment decision—and the person or entity whose interests command the decision maker's loyalty are ambiguously identified. The existence of research in which the decision maker is involved and the decision maker's own biases, factors that may bear directly on the treatment decision, may not be apparent. A pediatrician may be responding to the interests of the parents rather than the child, for example. The recent kidney and bone marrow transplantation cases

31. See Ebert, *The Medical School*, 229 *Sci. Am.* 139 (1973).

questioning the appropriateness of a guardian's consenting on behalf of an incompetent or minor donor illustrate the conflicts inherent in the existing structure.³² Secondly, the attending physician controls pertinent medical information, thereby limiting the ability of the patient or other interested persons to enter into the decision-making process. Thirdly, the present system lacks systematic reporting or review of the ultimate treatment decision, and peer review mechanisms are unsatisfactory.³³ Often, the only way a person can determine relevant facts about a past decision is to institute a malpractice action and gain the desired information through discovery procedures. Finally, the current decision-making process permits the doctor to justify his decision on grounds of "quality of life," resource allocation, societal goals, and other public policy issues, all of which determinations are usually best left to judicial and legislative bodies.

To counteract some of the problems created by unsatisfactory doctor-patient relationships, doctors and health care facilities have retained counsel to assist in their defense, particularly against malpractice actions. It has also become a commonplace charge that doctors must practice "defensive medicine"—the performance of tests, X-rays, procedures, and protocols to protect against liability rather than to benefit the patient.³⁴ Many health care facilities believe the problem to be one of public relations and have assigned members of their staff to serve as some form of "patient representative." In a recent survey of 2,000 hospitals having more than 200 beds, 462 of the 1,000 responding said that they had at least one employee whom they actually called a "patient representative" and whose primary job was "to serve as management's direct representa-

32. *Hart v. Brown*, 29 Conn. Supp. 368, 289 A.2d 386 (Sup. Ct. 1972); *Strunk v. Strunk*, 445 S.W.2d 145 (Ky. Ct. App. 1969). See Savage, *Organ Transplantation with an Incompetent Donor: Kentucky Resolves the Dilemma of Strunk v. Strunk*, 58 Ky. L. Rev. 129 (1970); Note, *Judicial Power to Order Medical Treatment for Minors over Objections of Their Guardians*, 14 SYRACUSE L. REV. 84 (1962).

33. See STAFF OF SENATE COMM. ON FINANCE, MEDICARE AND MEDICAID: PROBLEMS, ISSUES AND ALTERNATIVES, 91st Cong., 1st Sess., 105-16 (1970); Gallese, *Watching Doctors—Medical-Ethics Panels Are Set Up to Resolve Dilemmas on Research*, Wall Street J., Apr. 14, 1971, at 1, col. 6; Rostenberg, *The Ethics and Sociology of Peer Review*, 27 AM. MED. WOMEN'S ASS'N J. 318 (1972); Welch, *Professional Standards Review Organizations—Problems and Prospects*, 289 NEW ENG. J. MED. 291 (1973).

34. See HEW REPORT, *supra* note 15, at 14-15. The only empirical study of this claim showed 34% of the skull X-rays taken in a Seattle emergency room were primarily for "medicolegal" reasons. Bell & Loop, *The Utility and Futility of Radiographic Skull Examination for Trauma*, 284 NEW ENG. J. MED. 236, 239 (1971). See generally *The Medical Malpractice Threat: A Study of Defensive Medicine*, 1971 DUKE L.J. 939.

tive to patients.”³⁵ The job descriptions generally indicated, however, that the activities of these people were confined to nonmedical, “housekeeping” matters, and the person thus would be more accurately termed a “management representative.”

Public relations persons, nurses, or unit managers who lack both autonomy and authority, however, are unable to respond to the problems raised by the traditional medical decision-making process. Moreover, they usually cannot discover who has the power to make a treatment decision, where the decision maker's loyalties lie, who controls the pertinent information, whether there is any reporting or review of the treatment decision, or on what basis the treatment decision is justified. These persons owe primary loyalty to the health care facility, not to the patient. In the event of a conflict, their first responsibility must be to their employer. Without the ability to devote all possible energy and influence to protecting the patient, the third party becomes a barrier rather than a shield. The Patient Service Coordinator for the New York Hospital has described this intermediary as “someone who will greet the patient with a smile, listen to him, get to know him as a person and be his voice.”³⁶ While such a person may be needed, the role described is extremely limited and does nothing to resolve the problem characteristics of the traditional doctor-patient relationship. When an individual is sick, dying, or both, he needs more than a “placebo-practitioner” to hold his hand. He needs to know that he can count on the loyalty and judgment of a competent person who, at his direction, has access to his medical records and to staff consultants, and who can and will give him straight, unbiased answers to his questions. Anything less means that both his health and his human rights are potentially in danger.

Some health care facilities have developed statements, books, or pamphlets explaining to the patient his rights at that facility. One of the most interesting is “Your Rights as a Patient at Yale-New Haven Hospital,” which was prepared by the Dixwell Legal Rights Association, Inc., of New Haven, Connecticut.³⁷ This pam-

35. Thompson, Lupton, Rench & Feldesman, *Patient Grievance Mechanisms in Health Care Institutions*, in HEW APPENDIX, *supra* note 14, at 785-835.

36. Cote, *The Patient's Link*, 9 TRIAL, Mar.-Apr. 1973, at 30. Some nurses have expressed more positive views of their roles. See, e.g., Kosik, *Patient Advocacy or Fighting the System*, 72 AM. J. NURSING 694 (1972); Nations, *Nurse-Lawyer Is Patient-Advocate*, 73 AM. J. NURSING 1039 (1973).

37. The source of many of the rights asserted is a list of the demands presented by the National Welfare Rights Organization to the Joint Commission on Accreditation of Hospitals, June 18, 1970, which is reprinted in full as Appendix A in Worthington & Silver, *Regulation*

phlet suggests to the patient a series of questions to ask the doctor, identifies each hospital worker's position by the color and style of his clothes, and lists the name and extension number of a "patient assistant" who can be reached by telephone. Unfortunately, the booklet is incomplete and weak in such critical areas as refusal of treatment and access to medical records. The power of the "patient assistant" is also unclear. The Martin Luther King Health Center of New York has prepared a publication entitled "Your Rights as a Patient," which includes a patient complaint form in the pamphlet itself—a desirable innovation. The publication, however, is more a series of cartoon sketches depicting patients' predicaments than a working document for patient protection. In Boston, the Beth Israel Hospital has published a one-page brochure entitled "Your Rights as a Patient at Beth Israel."³⁸ The "rights" enumerated in this document come essentially from the preamble of the standards of the Joint Commission on Hospital Accreditation published in December, 1970.³⁹ This pamphlet, however, makes no mention of any person at the hospital in charge of ensuring that these rights are not violated. Moreover, the Beth Israel brochure fails to mention that Massachusetts law specifically grants patients access to their medical records.⁴⁰

The twelve-point "Patient's Bill of Rights," promulgated by the American Hospital Association on January 8, 1973,⁴¹ follows the

of Quality of Care in Hospitals: The Need for Change, 35 LAW & CONTEMP. PROB. 305, 328-31 (1970).

38. Reprinted in 9 TRIAL, July-Aug. 1973, at 59-60.

39. JOINT COMM'N ON ACCREDITATION OF HOSPITALS, ACCREDITATION MANUAL FOR HOSPITALS—PREAMBLE 1-2 (1970, updated 1973).

40. MASS. ANN. LAWS ch. 111, § 70 (Supp. 1972).

41. The full text of the A.H.A. Bill of Rights is:

1. The patient has the right to considerate and respectful care.

2. The patient has the right to obtain from his physician complete current information concerning his diagnosis, treatment, and prognosis in terms the patient can be reasonably expected to understand. When it is not medically advisable to give such information to the patient, the information should be made available to an appropriate person in his behalf. He has the right to know, by name, the physician responsible for his care.

3. The patient has the right to receive from his physician information necessary to give informed consent prior to the start of any procedure and/or treatment. Except in emergencies, such information for informed consent should include but not necessarily be limited to the specific procedure and/or treatment, the medically significant risks involved, and the probable duration of incapacitation. Where medically significant alternatives for care or treatment exist, or when the patient requests information concerning medical alternatives, the patient has the right to such information. The patient also has the right to know the name of the person responsible for the procedures and/or treatment.

pattern of the Joint Commission and Beth Israel statements. It is vague and does not provide an enforcement mechanism. Furthermore, the premise of the document is that the provider decides what rights the patient-consumer should have. In the field of landlord-tenant law, it would seem clearly anomalous to permit the landlord alone to determine tenant rights. In the health care field, however, such provider dominance over the consumer is so commonplace that it is seldom even commented on. Johnny Carson's January 9, 1973, parody of the document emphasized this irony when his own list of "patient rights" concluded that "the patient has a right to assume that if he is in a coma he will not be used as a door jamb."⁴²

4. The patient has the right to refuse treatment to the extent permitted by law and to be informed of the medical consequences of his action.

5. The patient has the right to every consideration of his privacy concerning his own medical care program. Case discussion, consultation, examination, and treatment are confidential and should be conducted discreetly. Those not directly involved in his care must have the permission of the patient to be present.

6. The patient has the right to expect that all communications and records pertaining to his care should be treated as confidential.

7. The patient has the right to expect that within its capacity a hospital must make reasonable response to the request of a patient for services. The hospital must provide evaluation, service, and/or referral as indicated by the urgency of the case. When medically permissible, a patient may be transferred to another facility only after he has received complete information and explanation concerning the needs for and alternatives to such a transfer. The institution to which the patient is to be transferred must first have accepted the patient for transfer.

8. The patient has the right to obtain information as to any relationship of his hospital to other health care and educational institutions insofar as his care is concerned. The patient has the right to obtain information as to the existence of any professional relationships among individuals, by name, who are treating him.

9. The patient has the right to be advised if the hospital proposes to engage in or perform human experimentation affecting his care or treatment. The patient has the right to refuse to participate in such research projects.

10. The patient has the right to expect reasonable continuity of care. He has the right to know in advance what appointment times and physicians are available and where. The patient has the right to expect that the hospital will provide a mechanism whereby he is informed by his physician of the patient's continuing health care requirements following discharge.

11. The patient has the right to examine and receive an explanation of his bill regardless of source of payment.

12. The patient has the right to know what hospital rules and regulations apply to his conduct as a patient.

Reprinted in 9 TRIAL, *supra* note 38, at 60. See N.Y. Times, Jan. 9, 1973, at 1, col. 6.

42. Other contributions Johnny Carson had on his Jan. 9, 1973, program include:

No patient may, no matter what the extenuating circumstances, be given a sponge bath with Janitor in a Drum; and

No patient shall be denied the right to seek further medical consultation if he is given an autopsy.

See Gaylin, *The Patient's Bill of Rights*, SAT. REV. SCI., Mar. 1973, at 22. One document

The collections of minimal "rights" currently being promulgated by health care facilities remind one of the free enterprise, human-rights-be-damned philosophy of Ayn Rand, restated for the medical profession by Dr. Robert M. Sade in his "Medical Care as a Right: A Refutation."⁴³ Unable to distinguish between the sale of bread and medical services, Dr. Sade fails completely to consider the human rights of patients while they are under medical care.⁴⁴ We do not need more lists drawn up by health care providers. We need a clear, carefully articulated catalogue of hospital patients' rights, presented from the patient-consumers' perspective. To ensure that these rights are protected, a properly functioning mechanism within the health care facility is needed.

V. THE PATIENT RIGHTS ADVOCATE

This section and the next present a mechanism within the health care facility capable of assisting the patient in decisions affecting health care and a model bill of patient rights that provides the legal foundation for the patient advocate system. The introduction of these proposals into the hospital context is designed to benefit doctor and patient alike.⁴⁵

The goals of a patient rights advocate system are:

- to protect patients, especially those at a disadvantage within the health care context—the young, the illiterate, the uncommunicative, those without relatives, those unable to speak English—by making available an advocate and a series of decision-making procedures;

- to make available to those who seek it the opportunity to participate actively with their doctor as a partner in a personal health care program;

- to restore medical technologies and pharmaceutical advances to proper perspective by deflating the exaggerated expectations of the modern American medical consumer;⁴⁶ and

- to reflect in the doctor-patient relationship the reality of the

issued by Herbert S. Denenberg, Insurance Commissioner of Pennsylvania, is some improvement but gives the hospital patient no clearer idea of his legal rights than the other documents mentioned. H. DENENBERG, *CITIZENS BILL OF HOSPITAL RIGHTS* (1973).

43. Sade, *Medical Care as a Right: A Refutation*, 285 *NEW ENG. J. MED.* 1288-92 (1971). This article produced more letters to the editor, mostly favorable, than any article previously published by the *New England Journal of Medicine*.

44. Cf. Noonan, *The Case of the Talented Bakers*, *HARV. MED. SCH. ALUMNI MAG.*, Jan. 1973, at 12-16.

45. See HEW REPORT, *supra* note 15, at 83-87.

46. See *id.* at 68.

health-sickness continuum, and to assert the humanness of death as a natural and inevitable reality.

To this end, we propose a "patient rights advocate," an individual whose primary responsibility is to assist the patient in learning about, protecting, and asserting his or her rights within the health care context. The advocate exercises, at the direction of the patient, powers that belong to the patient. To a large extent, these powers are rooted in the rights that the patient possesses and include:

- complete access to medical records and the authority to call in, at the direction of the patient, a consultant to aid or advise the patient;

- active participation on those hospital committees responsible for monitoring quality health care, especially utilization-review and patient care;

- access to support services for all patients who request them;

- participation at the patient's request and direction in discussion of the patient's case, especially before decisions must be made and alternatives chosen.

The word "advocate" is used deliberately. In its classical sense, "advocare" means "to summon to one's assistance, to defend, to call to one's aid." Connotations of "adversariness," of contentiousness, and of deliberate antagonism are unfortunate, for they involve not the concept of advocacy per se, but the manner in which the advocate pursues his duties. Yet most of the criticism directed against the patient rights advocate has concerned the alleged introduction of conflict into the hospital setting. The advocate as adversary could confront the hospital with a number of problems. The relegation of all serious decision making to adversary proceedings, for example, would raise many questions: How can an independent decision be reached? Should the doctor retain final authority to do what he judges to be in the best interests of the patient? Who would define what is "serious?" How could such a program be supervised? Would a state of paralysis engulf the health care facility?

Such criticism, however, seems less a reaction to the concept of the patient rights advocate itself than to one manner in which the advocate could discharge his responsibilities. The advocate could, for example, function instead as an ombudsman.⁴⁷ In this role he would seek out broad problem areas, research facts, publicize grievances to appropriate audiences, and make suggestions about resolv-

47. See generally S. ANDERSON, *OMBUDSMAN FOR AMERICAN GOVERNMENT?* (1968); Kosik, *supra* note 36.

ing those problems. He would not participate, however, in the actual resolution. This conduct would provide active representation without direct personal influence on the outcome of the decision. While this approach would eliminate the problems created by an adversary system, the danger is that such a person would have no influence upon important decisions.

A third suggestion would combine aspects of both the adversary and ombudsman approaches. While acting as an ombudsman available to all patients who desired his services, the advocate could compile lists of recurring situations in which the rights of patients are affected and classify them according to seriousness. In a special category, for example, would be matters like transplantation and the refusal of life-sustaining medication or procedures. In each case fitting this category, the patient's interests would be represented by an advocate in an adversary hearing. An appropriate tribunal might be a decision-making committee like the kidney or heart transplant committees that select donors and recipients, or a policy-setting committee like the executive house staff.⁴⁸ For less serious situations, other appropriate safeguards would be established. In both instances, an open process in which the patients' interests are represented would replace current covert policies for dealing with "difficult" cases.

It is essential to have as many advocates as necessary to ensure a functional patient-advocate ratio. The advocate would interview the patient at the time of arrival at the hospital, present a packet of materials including an explanation of the patient's rights, and remain available at all times via telephone.⁴⁹ He would perform additional services for all those who request them and also provide objective information to members of the community who want to know before entering the health care facility how a particular problem is treated and whether alternatives are available. The advocate would also make daily rounds.

Examples of how this system would improve health care while safeguarding human rights are legion in all areas of medical care. In presenting his patient rights advocate proposal to the Trustees of Boston City Hospital, Dr. David F. Allen, former chief resident

48. Cf. Sand, Livingston & Wright, *Psychological Assessment of Candidates for a Hemodialysis Program*, 64 ANNALS INTERNAL MED. 602 (1966); Note, *Patient Selection for Artificial and Transplanted Organs*, 82 HARV. L. REV. 1322 (1969).

49. Cf. Bartlett, Johnston & Meger, *Dial Access Library—Patient Information Service—An Experiment in Health Education*, 288 NEW ENG. J. MED. 994 (1973); Rabkin, *The Needs of Patients*, 288 NEW ENG. J. MED. 1019 (1973).

in psychiatry and president of the House Officers Association, told of the time he was called to the emergency ward to talk with a Puerto Rican woman whose stomach had just been pumped. He was the first person on the scene able to speak Spanish to the woman and was told by her that she had had some very distressing news at home, had taken two Alka Seltzers, and had come to the hospital to talk with someone. The staff in the emergency room had "assumed" she was an overdose case "because most Puerto Ricans who demonstrate symptoms like those shown by the woman have overdosed."⁵⁰ An advocate on duty and capable of speaking Spanish could have prevented this "routine treatment." To demonstrate just how the patient rights advocate not only could protect human rights, but also could improve the quality of medical care, it is worthwhile to review several additional examples in a variety of situations.

Case 1: The Emergency Room

Paul, a ten-year-old boy, had a seizure at his home and passed out. His father picked him up and rushed him to a police station. The nearest hospital was a private institution. Paul had been receiving treatment at the County Hospital, which was some distance away. The police said they could not take him there because it was out of their district. When they arrived at the private hospital, Paul's father was subjected to an interview about his finances and insurance. No one would look at Paul until his father had answered such questions as: "Do you own your own home?" "Who is your employer?" "How long have you worked there?" The interviewer also refused to call the County Hospital. In frustration, Paul's father left the emergency room at the hospital and drove the long distance to the County Hospital. In the course of his trip, he passed several hospitals but was afraid to stop because of the possibility that they would treat him as the first hospital had. He arrived at the County Hospital, where his son died within an hour.⁵¹

This case illustrates the tragic results that occur when a hospital places housekeeping chores above medical duty in an emergency situation. An advocate could have asserted the right of the patient to receive emergency care promptly without reference to ability to pay. Failure to provide an opportunity to assert that right was a significant factor in the loss of a life. An advocate could have played a key role in saving it.

Case 2: Diagnostic Tests

Patient 2, a professor, was admitted to the hospital for a series of tests to

50. Oral presentation by David Allen, M.D., before the Trustees of Boston City Hospital, Boston, Mass., Sept. 26, 1973. Dr. Allen is currently Joseph P. Kennedy, Jr. Foundation Fellow in Medical Ethics, Harvard University.

51. This is an actual case related in E. KENNEDY, IN CRITICAL CONDITION 49-51 (1972).

determine the identity of the condition from which he was suffering. A neurologist and three medical students ran him through a neurological examination. In his words: "I got a reinforcement of the sense of not only am I a patient who is supposed to behave in a certain way, but I'm almost an object to demonstrate to people that I'm not really people any more, I'm something else. I'm a body that has some very interesting characteristics about it. . . . I began to feel not only the fear of this unknown, dread thing that I have, that nobody knows anything about—and if they know, they're not going to tell me—but an anger and a resentment of 'Goddamn it, I'm a human being and I want to be treated like one!' And feeling that if I expressed anger, I could be retaliated against, because I'm in a very vulnerable position."⁵²

Some of the frustrations of Patient 2 could find an outlet in a patient rights advocate. The advocate would be a person to whom the patient could talk without fear of retaliation; a person who could pull his medical records and tell him whether or not a diagnosis had been made; a person who, on behalf of a busy medical staff, could take the time to explain the reason for the tests, why medical students were present, that he could have them excluded if he wished, and that notwithstanding his attitudes toward the medical staff or his expressions of fear and resentment, no retaliatory action would be taken against him. Tension and conflict would be reduced and the quality of medical care improved.

Case 3: Childbirth

Mr. and Mrs. 3 have attended classes on natural childbirth. They have discussed the matter with the doctor in the out-patient clinic of the hospital where the child will be delivered. The hospital has a policy of allowing the husband in the delivery room "at the doctor's discretion." They enter the hospital and spend three hours together in the labor room. As she is being transferred to the delivery room the doctor (a resident) says to the husband, "Sorry, you can't come in, you make me nervous."

In the delivery room Mrs. 3, who has previously given birth by the natural method in England, demands that the stirrups be removed. The attendants laugh at her and hold her down as her wrists are strapped to the table by leather thongs.⁵³

The current system offers Mr. and Mrs. 3 little, if any, recourse. Under a patient advocate system, an advocate assigned to the maternity ward would be in charge of advising the medical personnel about the couple's desires concerning natural childbirth, would make whatever preparations were deemed necessary, and would be present at the parents' request to ensure during birth that the father

52. Hanlan, *Notes of a Dying Professor*, PENN. GAZETTE, Feb. 1973, at 18-24 (originally published anonymously). His disease was eventually diagnosed as A.L.S., amyotrophic lateral sclerosis.

53. Based upon the experience of Joan Haggerty as she recounts it in *Childbirth Made Difficult*, Ms., Jan. 1973, at 16-17.

was not denied access to the delivery room and that the mother was not subjected to coercion or ridicule—a function probably unnecessary if the husband were allowed to be present in the delivery room as a matter of course. The advocate would function similarly in the emergency room to eliminate delays when possible or to provide an interpreter when needed. Again, the advocate would improve the resulting doctor-patient relationships.

Case 4: Breast Cancer

Ms. 4 enters the hospital to have a breast biopsy. She is extremely nervous and upset. She is asked to sign a consent form that she doesn't understand. She is assured it is "routine" and signs it. When she sees her doctor she asks him about the alternative methods of treatment available if her tumor turns out to be malignant. He tells her that he does only radical mastectomies, but that she shouldn't worry before they know whether her tumor is malignant or not. The doctor then leaves the hospital for the day. Patient 4 continues to think about her condition and asks the nurse what will happen if her tumor is malignant. Specifically she wants to know if the doctor will immediately proceed with the mastectomy while she is still unconscious. The nurse says that this should be discussed with the doctor.⁵⁴

Currently, the patient's only recourse is either to try to get her doctor on the phone or to wait until the next day when she hopefully will see him again before the biopsy. Moreover, no one is presently available to explain the consent form to her. A patient rights advocate, on the other hand, would be present to explain consent forms and their implications to all patients required by the hospital to sign them. Additionally, the advocate would have provided the patient with a list of questions to ask anyone requesting that she sign such a form:

- What treatment does the doctor want to use and why?
- What alternative treatments are available and why is the method chosen superior to others?
- What are the risks of having the procedure and of not having the procedure?
- Is the procedure experimental?
- What is the name and status—doctor, intern, resident, or medical student—of the person who will perform the procedure?
- What are the side-effects and how long will they last?
- How much will it cost?
- What will be the duration of hospitalization?

54. This case is a hypothetical one based on what the authors understand is common practice at some institutions. Cf. J. CAMPION, *THE INVISIBLE WORM* (1972); Crile, *Breast Cancer: A Patient's Bill of Rights*, Ms., Sept. 1973, at 66.

—What will be the permanent effects?

—What are the possibilities of a complete cure?

Had Patient 4 asked her doctor these questions initially, and had the doctor responded to them, the difficulties she is now experiencing would not have occurred, and conflict and tension between her and her doctor would have been significantly reduced.

In all of these examples and in myriad others,⁵⁵ a patient rights advocate with the powers outlined above could have effectively improved doctor-patient communication and improved the quality of medical care delivered. The recent series of informed consent cases⁵⁶ has demonstrated that the old adage "good medicine is good law"⁵⁷ is no longer universally true. Courts likely will more and more frequently allow juries to decide, without the aid of any expert testimony from the medical profession, what patients should be told about their conditions.⁵⁸ As this trend continues, attempts to characterize the perpetuation of low standards of doctor-patient communication and the exclusion of the patient from important medical decision making concerning his treatment as "standard medical procedure" will no longer provide any protection against legal liability. Therefore, hospitals considering the adoption of a patient rights advocate system should recognize not only the public relations value of such a move, but also, from the perspective of resolving doctor-patient grievances at the hospital rather than in the courts, the legal wisdom as well.⁵⁹

Our proposed system requires a person whose primary responsibility and loyalty are commanded by the patient alone and who can be fired only upon patient complaint. Beyond that, however, there is no single set of qualifications for the advocate. The advocate will deal with people of varying degrees of education and ability to communicate and of different ethnic, religious, and social backgrounds. Some knowledge of law, medicine, and psychology would appear essential, but the extent to which formal education would prepare

55. See note 36 *supra* and note 56 *infra*; cf. Calland, *Iatrogenic Problems in End-Stage Renal Failure*, 287 NEW ENG. J. MED. 334 (1972).

56. *Canterbury v. Spence*, 464 F.2d 772 (D.C. Cir.), *cert. denied*, 409 U.S. 1064 (1972); *Cobbs v. Grant*, 8 Cal. 3d 229, 502 P.2d 1, 104 Cal. Rptr. 505 (1972); *Wilkenson v. Vessey*, 295 A.2d 676 (R.I. 1972); see Annas, "Informed Consent," 1 MEDICOLEGAL NEWS, Oct. 1973, at 3.

57. Hagman, *The Medical Patient's Right to Know: Report on a Medical-Legal-Ethical Empirical Study*, 17 U.C.L.A.L. REV. 758, 764 (1970).

58. See cases cited note 56 *supra*; Annas, A.H.A. *Bill of Rights*, 9 TRIAL, Nov.-Dec. 1973, at 59. For a positive medical perspective see Alfi, *Informed Consent: A Study of Patient Reaction*, 216 J.A.M.A. 1325 (1971).

59. See note 45 *supra*.

a person for this job seems minimal. Some commentators have suggested a highly clinical, interdisciplinary program centered about our teaching hospitals. Experience here would seem the best teacher.

Financing and supervising the advocate program and deciding who should pay the advocate for his work also present enormous problems. The preferred situation would provide support and supervision from such outside organizations as the Department of Health, Education, and Welfare, the state department of public health, a consumer affairs office, Blue Cross, a state-wide medical foundation, or health consumers group. If there is no alternative to making the advocate a member of the hospital administrative staff, it is imperative that he or she be accountable only to the patients served.

The patient rights advocate system could be established in a number of ways. The State of Minnesota recently passed a statute incorporating a Patient Bill of Rights and requiring that it be posted in hospitals and distributed to patients.⁶⁰ Provisions for patient advocates working for the state government could be added to such pieces of legislation. Under a system of National Health Insurance,

60. The text of the Minnesota Bill of Rights is:

(1) Every patient and resident shall have the right to considerate and respectful care;

(2) Every patient can reasonably expect to obtain from his physician or the resident physician of the facility complete and current information concerning his diagnosis, treatment and prognosis in terms and language the patient can reasonably be expected to understand. In such cases that it is not medically advisable to give such information to the patient the information may be made available to the appropriate person in his behalf;

(3) Every patient and resident shall have the right to know by name and specialty, if any, the physician responsible for coordination of his care;

(4) Every patient and resident shall have the right to every consideration of his privacy and individuality as it relates to his social, religious, and psychological well being;

(5) Every patient and resident shall have the right to respectfulness and privacy as it relates to his medical care program. Case discussion, consultation, examination, and treatment are confidential and should be conducted discreetly.

(6) Every patient and resident shall have the right to expect the facility to make a reasonable response to the requests of the patient;

(7) Every patient and resident shall have the right to obtain information as to any relationship of the facility to other health care and related institutions insofar as his care is concerned, and:

(8) The patient and resident have the right to expect reasonable continuity of care which shall include but not be limited to what appointment times and physicians are available.

MINN. STAT. ANN. § 144.651 (Supp. 1973). This is, of course, an even weaker and vaguer statement than the A.H.A. Bill of Rights. See Curran, *The Patient's Bill of Rights Becomes Law*, 290 NEW ENG. J. MED. 32 (1974).

or as part of the Medicare and Medicaid programs, the federal government could initiate legislation requiring such advocates who would function pursuant to federal regulations and be paid and supervised by a national Patient Advocate Office. The Secretary's Commission on Medical Malpractice has strongly recommended the adoption of both a Patient Bill of Rights and a strong grievance mechanism by all hospitals.⁶¹ If voluntary compliance with such a suggestion is not forthcoming, legislation is certainly an appropriate step in this area.

Different approaches may be needed for different types of institutions. Proposals for legal advocates in mental health institutions, for example, have made substantial progress and contributed significantly to the civil rights of mental patients.⁶² The problems of people in such long-term facilities are, of course, different from those in general hospitals where the average stay lasts eight days, and variations of the system may also be necessary in the nursing home context, in the health maintenance organization context, and in the neighborhood clinic context. No matter which method is chosen to implement the Patient Advocate System, however, the key to its success will be the patient-centered Bill of Rights it seeks to enforce.

VI. A MODEL BILL OF PATIENT RIGHTS

The deficiencies of recent attempts to formulate a Patient Bill of Rights by the American Hospital Association and other provider-oriented organizations have been discussed in this article and in another by one of the authors.⁶³ To summarize, there is much confusion and inaccuracy concerning the concept "right," with little attempt to clarify the sense in which the term is used; there is a fundamental conflict of interest in permitting the provider of health care to determine the rights of the health care consumer; and there is a general absence of an enforcement mechanism for the "rights" provided. The following model bill is presented with these difficulties in mind.

61. HEW REPORT, *supra* note 15, at 71, 84.

62. See *Wyatt v. Stickney*, 344 F. Supp. 373 (M.D. Ala. 1972). See generally B. ENNIS & L. SIEGEL, *THE RIGHTS OF MENTAL PATIENTS* (1973).

63. See Annas, *supra* note 58. The thesis of that article is that while incomplete, the American Hospital Association document is still extremely important because it makes the standards of the Joint Commission on Hospital Accreditation more accessible and understandable to patients, and because it can be used in court as evidence of custom in establishing a standard of care.

Model Bill of Patient Rights

As you enter this health care facility, it is our duty to remind you that your health care is a cooperative effort between you as a patient and the doctors and the hospital staff. During your stay you will have a Patient Rights Advocate available. His or her duty is to assist you in all the decisions you must make and in all situations in which your health and welfare are at stake. His or her first responsibility is to help you learn who each of the people are who will be working with you, and to help you understand what your rights as a patient are. He or she can be reached at any time of the day by dialing _____. The following is a list of your rights as a patient. Your advocate's duty is to ensure that you are afforded these rights.

1. The patient has a right to intelligent participation in all decisions concerning his health care program.⁶⁴
2. We recognize the right of all potential patients to know what research and experimental protocols are being used in our facility and what alternatives are available in the community.⁶⁵
3. The patient has a right to privacy respecting the source of payment for treatment and care. This right includes access to the highest degree of medical care without regard to the source of payment for that treatment and care, and a copy and explanation of the bill.⁶⁶
4. We recognize the right of a potential patient to information about medical care and procedures.⁶⁷
5. The patient has a right to prompt attention, especially in an emergency situation.⁶⁸

64. This right is based upon principles of self-determination and privacy contained in the common-law theories of assault and battery and of informed consent, and in *Roe v. Wade*, 410 U.S. 113 (1973), in *Eisenstadt v. Baird*, 405 U.S. 438 (1972), and in *Griswold v. Connecticut*, 381 U.S. 479 (1965). For further discussion see N. KITTRIE, *THE RIGHT TO BE DIFFERENT* 402-05 (1971); Cantor, *A Patient's Decision to Decline Life-Saving Medical Treatment: Bodily Integrity Versus the Preservation of Life*, 26 *RUTGERS L. REV.* 228, 236-38 (1973); Sharpe & Hargest, *Lifesaving Treatment for Unwilling Patients*, 36 *FORDHAM L. REV.* 695, 695-99 (1968).

65. This knowledge is essential to enable the patient to give informed consent. See note 56 *supra* and accompanying text.

66. This right, of course, currently applies only after the patient has been admitted into the hospital. It would take a complete system of National Health Insurance to make nonemergency access to care a "right." See note 17 *supra*.

67. This information is essential to informed consent. See note 56 *supra* and accompanying text.

68. Concerning the duty of an emergency room to treat patients requiring emergency care see *Wilmington Gen. Hosp. v. Manlove*, 54 Del. 15, 174 A.2d 135 (1961); Powers, *Hospital Emergency Service and the Open Door*, 66 *MICH. L. REV.* 1455 (1968). See generally N.

6. The patient has a right to a clear, concise explanation of all proposed procedures in layman's terms, including the possibilities of any risk of mortality or serious side effects.⁶⁹
7. The patient has a right to a clear, complete, and accurate evaluation of his condition and prognosis without treatment before he is asked to consent to any test or procedure.⁷⁰
8. We recognize the right of the patient to know the identity and professional status of all those providing service. All personnel have been instructed to introduce themselves, state their status, and explain their role in the health care of the patient.⁷¹
9. We recognize the right of any patient who does not speak English to have access to an interpreter.⁷²
10. While in the health care facility the patient has a right to all the information contained in his medical record.⁷³
11. We recognize the right of a patient to discuss his condition with a consultant specialist at his own request and expense.⁷⁴
12. The patient has a right to refuse any test or procedure designed for educational purposes rather than for his direct personal benefit.⁷⁵

CHAYET, LEGAL IMPLICATIONS OF EMERGENCY CARE 43-92 (1969); JOINT COMM'N ON ACCREDITATION OF HOSPITALS, ACCREDITATION MANUAL FOR HOSPITALS—EMERGENCY SERVICES SECTION 1-6 (1970, updated 1973).

69. See note 56 *supra* and accompanying text.

70. See *id.*

71. See *id.*

72. See note 50 *supra* and accompanying text. Without an understanding of what is being said, informed consent becomes almost impossible.

73. This is based upon the patient's right to the information contained in his medical record. See *Pyramid Life Ins. Co. v. Masonic Hosp. Ass'n*, 191 F. Supp. 51 (W.D. Okla. 1961); *Wallace v. University Hosps.*, 82 Ohio L. Abs. 257, 164 N.E.2d 917 (Cuyahoga County Ct. C.P. 1959), *modified on other grounds*, 84 Ohio L. Abs. 224, 170 N.E.2d 261 (Cuyahoga County Ct. App. 1960), *appeal dismissed*, 171 Ohio St. 487, 172 N.E.2d 459 (1961). See generally Fleisher, *Ownership of Hospital Records and Roentgenograms*, 4 ILL. CONT. LEGAL ED. 73 (1966); Helfman, Jarrett, Lutzher, Schneider & Stein, *Access to Medical Records*, in HEW APPENDIX, *supra* note 14, at 177.

74. See *Steeves v. United States*, 294 F. Supp. 446 (D.S.C. 1968) (liability found where consultation was sought but refused); *Valentine v. Kaiser Foundation Hosps.*, 194 Cal. App. 2d 282, 15 Cal. Rptr. 26 (Ct. App. 1961); *Lab v. Hall*, 200 So. 2d 556 (Fla. Ct. App. 1967). See also E. PICKERING, REPORT OF THE SPECIAL STUDY REGARDING THE MEDICAL PROFESSION IN ONTARIO 92 (1973). There is also an opinion by the Judicial Council of the American Medical Association on this: "A physician should seek consultation upon request; in doubtful or difficult cases; or whenever it appears that the quality of medical service may be enhanced thereby." A.M.A., OPINIONS AND REPORTS OF THE JUDICIAL COUNCIL, PRINCIPLES OF MEDICAL ETHICS § 8, at 53 (1966). Consultations may also help prevent unnecessary surgery. See Bunker, *Surgical Manpower*, 282 NEW ENG. J. MED. 135 (1970); Vayda, *A Comparison of Surgical Rates in Canada and in England and Wales*, 289 NEW ENG. J. MED. 1224 (1973); Note, *Unnecessary Surgery: Doctor and Hospital Liability*, 61 GEO. L.J. 807, 811-13 (1973).

75. See note 64 *supra*. This right has been the subject of much discussion and litigation. See, e.g., *John F. Kennedy Hosp. v. Heston*, 58 N.J. 576, 279 A.2d 670 (1971); Ford, *Refusal*

13. The patient has a right to refuse any particular drug, test, or treatment.⁷⁶
14. The patient has a right to both personal and informational privacy with respect to the hospital staff, other doctors, residents, interns and medical students, any researchers, nurses, or other patients.⁷⁷
15. We recognize the patient's right of access to people outside the health care facility by means of visitors and the telephone. Parents may stay with their children, and relatives may stay with terminally ill patients, 24 hours a day.⁷⁸
16. The patient has a right to leave the health care facility regardless of physical condition or financial status, although he may be required to sign a release stating that he is leaving against the medical judgment of his doctor or the hospital.⁷⁹
17. We recognize the patient's right not to be discharged or transferred from the health care facility without proper medical indication, a complete explanation, and prior notification of a person of his choice.
18. We recognize the right of a patient to receive a complete copy of the information contained in his medical record at the termination of his stay at the health care facility.⁸⁰
19. We recognize the right of all patients to have continuous access to a patient rights advocate who may act on behalf of the patient to assert or protect the rights set out in this document.⁸¹

VII. CONCLUSION

Patients have rights as citizens that they do not forfeit when they become sick and enter a health care institution. The genesis of the modern medical center has radically altered the way in which medicine is practiced, and advances in technology have vastly in-

of Blood Transfusions by Jehovah's Witnesses, 10 CATHOLIC LAW. 212 (1964); Note, *An Adult's Right to Resist Blood Transfusions: A View Through John F. Kennedy Memorial Hospital v. Heston*, 47 NOTRE DAME LAW. 571 (1972). The basis of this right is personal integrity and informed consent.

76. This right can be based either on straight assault and battery analysis or on an informed consent theory.

77. See JOINT COMM'N ON ACCREDITATION OF HOSPITALS, ACCREDITATION MANUAL FOR HOSPITALS—PREAMBLE 2 (1970, updated 1973); note 64 *supra*.

78. Such access is necessary for adequate exercise of the parents' right to terminate consent for treatment of a child at any time, and presence also may be required to give adequately informed consent. See note 56 *supra*.

79. This right can be derived from the right to refuse treatment, see note 75 *supra*, and from the tort of false imprisonment.

80. See note 72 *supra*.

81. This right is necessary to assure the patient complete enjoyment of the enumerated substantive rights.

creased treatment alternatives. The traditional model of the doctor-patient relationship creates serious problems in the hospital context that diminish the patient's right of self-determination. Patients are unable to assert their rights in a hospital context because they are sick and remain passive because their main concern is the restoration of their health. The atmosphere of doctor-dominance in the health care institution can be changed so that human rights are protected without affecting adversely the quality of care administered.

To change the traditional doctor-patient relationship in the health facility context, one must begin with a complete statement defining the rights, both those legally recognized and those granted as a matter of hospital policy, that should be afforded to all patients. This document should then be made available to all patients and hospital staff and to members of the community in general. Its first purpose is educational. To perform its second purpose—the assurance that rights are afforded—a patient rights advocate system should be adopted in the hospital. The advocate must have the power to exercise, on behalf and at the direction of the patient, all of the patient's rights outlined in the rights document. He should be financially independent of the hospital and accountable only to the patients he is charged with serving. Such a system can be initiated voluntarily by a health care institution, or it can be mandated by a state or federal statute or regulation.

Objections to the patient advocate proposal fall into three general categories: (1) there should be no interference with the current doctor-patient relationship; (2) patients' rights are already being protected by all members of the hospital staff; and (3) the entire health care delivery system is fundamentally defective and this "band-aid" approach will serve only to delay inevitable and radical system restructuring. We have demonstrated in this article that the first two arguments are without merit. Before one resorts to the extremes of the third position, experimentation with the patient rights advocate as outlined herein is called for. While certainly no panacea, the advocate could help not only the individual patient but also society and the medical profession in working toward what must be a common goal: ensuring that human rights do not become victims of medical progress.

